

FELLOWS' SEMINAR
DEPARTMENT OF CLINICAL BIOETHICS
NATIONAL INSTITUTES OF HEALTH
2002-2003

Fall Session

Wednesdays 4:00-5:30pm

Fall: September 25 - October 30, 2002

Spring: January 29-June 11, 2003

* = Supplemental reading

REQUIRED TEXTS

1. Beauchamp TL, Childress JF. Principles of Biomedical Ethics. 5th edition. New York: Oxford University Press, 2001.
2. Berg, Appelbaum, Lidz, Parker. Informed Consent, 2nd Edition. New York: Oxford University Press, 2001.
3. Daniels N. Just Health Care. New York: Cambridge University Press, 1985.
4. Dworkin G. The Theory and Practice of Autonomy. New York: Cambridge University Press, 1988.
5. Rawls JA. A Theory of Justice, Revised Edition. Cambridge, MA: Harvard University Press, 1999.
6. Levine RJ. Ethics and Regulation of Clinical Research. 2nd edition, New Haven: Yale University Press, 1988.

September 25

HISTORY OF MEDICAL ETHICS

Emanuel

1. Pellegrino ED. The Metamorphosis Of Medical Ethics: A 30-Year Retrospective. *JAMA* 1993; 269:1158-1162.
2. Kass L. *Is there a Medical Ethic?* New York: Free Press, 1989. Chapter 9, 224-246.
3. Beecher HK. Ethics and Clinical Research. *The New Eng J Med* 1966; 274:1354-1360.
4. * Vanderpool H. A Critical Review of the Belmont Report
5. * Baker R. From Medical Ethics into Bioethics: The Belmont Report and the Deprofessionalization of the Medical Ethics.

October 2

LEGAL CASES IN INFORMED CONSENT

Lombardo

1. Berg, Appelbaum, Lidz, Parker. Chapter 3. *Informed Consent, 2nd Edition*. New York: Oxford University Press, 2001.
2. Veatch, RM. Abandoning Informed Consent. *Hastings Center Report* 1995; 25:5-12.
3. Canterbury v. Spence.
4. Truman v. Thomas.
5. Arato v. Avedon.
6. Katz, J. Chapter 3, pp 48-84. *The Silent World of Doctor and Patient*.
7. Schloendorff v. Society of New York Hospital

October 9 **ETHICAL CONSIDERATIONS IN INFORMED CONSENT** **Miller**

1. Beauchamp and Childress. *Principles of Biomedical Ethics*, 5th ed. Chapter 3, "Respect for Autonomy."
2. Berg, Lidz, Meisel. *Informed Consent*. Chapter 12, "Fulfilling the Underlying Purpose of Informed Consent."
3. Troug R, Robinson W, Randolph, A. "Is Informed Consent Always Necessary for Randomized, Controlled Trials?" *The New England Journal of Medicine* 1999; 340(10):804-807.

October 16 **PRINCIPLISM AND ITS CRITICS** **Beauchamp**

1. Beauchamp and Childress, Chapter 1 pp.1-25, and Chapter 9 pp. 384-413
2. draft on "Bioethics and the Common Morality,".

October 23 **META ETHICS** **Brock**

1. James Rachels, "The challenge of Cultural Relativism"
2. J.L. Mackie, Ethical Theory I – March 1998 part I chapter 6- "The Subjectivity of Values" ppg. 76-102.
3. David Brink, "Moral Realism and the Sceptical Arguments from disagreement and queerness", *Australasian Journal of Philosophy* 1984 62 (2): 111-125
4. John Rawls, "Construction and Objectivity", *J. Philos* 1980 77 (9): 554-572
5. Norman Daniels "Wide Reflective Equilibrium and theory acceptance in ethics"

October 30 **PHYSICIAN-PATIENT RELATIONSHIP** **Emanuel**

1. Mechanic D and Schlesinger M. The Impact of Managed Care on Patients' Trust in Medical Care and their Physicians. *JAMA* 1996; 275:1693-1697.
2. Emanuel E and Dubler NN. Preserving the Physician-Patient Relationship in the Era of Managed Care. *JAMA* 1995; 273:323-329.
3. Emanuel E and Emanuel LL. Four Models of the Physician-Patient Relationship. *JAMA* 1992; 267:2221-2226.

October 23-December 19

ETHICAL AND REGULATORY ASPECTS OF HUMAN SUBJECTS RESEARCH MONDAYS 8:30-11:30

January 29 **COST –EFFECTIVENESS ANALYSIS** **Ubel**

1. Ubel PA, Nord E, Gold M, Menzel P, Pinto Prades JL, Richardson J. Improving value measurement in cost-effectiveness analysis. *Medical Care* 38(9):892-901, 2000.
2. Ubel PA, Richardson J, Menzel P. Societal value, the Person Trade-Off, and the dilemma of whose values to measure for cost-effectiveness analysis. *Health Economics*. 9:127-136, 2000.
3. Ubel PA, Hirth RA, Chernew ME, Fendrick AM. What is the price of life And why doesn't it increase at the rate of inflation?

February 5 ORGANIZATION AND FINANCING OF US HEALTH CARE WEINER

1. Kuttner, R. The American health care system: Health Insurance coverage, *NEJM* 199:340 (2) 163-168
2. Weiner, J, Delissovoy, G, Razing a Tower of Babel: A Taxonomy for Managed Care and Health Insurance Plans, *J of Health Politics, Policy & Law* 1993: 18 (1) 75-103
3. Heffler, S ,et al. Health Spending Projections For 2001-2011: The Latest Outlook, *Health Affairs, Health Affairs*, 2002 21 (2) 207-218
4. Berwick, D. A User's Manual for the IOM "Quality Chasm" Report, *Health Affairs*, 2002 21 (3) 80-102

**** Additional Suggested Reading:**

1. Starr, P, *The Social Transformation of American Medicine*, Basic Books NYC, 1982 (A prize winning historical text)
2. Institute of Medicine Reports. *To Err is Human: Building a Safer Health Care System and Crossing the Quality Chasm*. See www.nas.edu.
3. Stoline, AM, Weiner, JP, *The New Medical Marketplace*, Johns Hopkins University Press, Baltimore, 1992 (An easy to read overview that starts from "square one")
4. Kongstvedt, P, (edt) *The Managed Care Handbook*, 4th edt. Aspen, Rockville, Md, 2001 (The "bible" of US insurance companies)
5. Starfield B. Is Us Health Care Really the Best in the World? *JAMA*, 200 284:483-488
6. Moon, M. Medicare, *NEJM*, 2001 344:928-31
7. Schroeder, SA, Prospects for Expanding Health Insurance Coverage, *NEJM* 2001: 344 928-31
8. Rowland, D, Garfield R, Health Care for the Poor: Medicaid at 35. *Health Care Financing Review*, Fall 2000 22 (1) 23-34
9. Reinhardt, U, Hussey, P, Anderson, G, Cross-National Comparison of Health Systems, *Health Affairs*, 2002, 21 169-181

Suggested Web sites: kff.org, cms.gov, ahrq.gov, cmwf.org, aahp.org

February 12 **ETHICAL ISSUES IN THE ALLOCATION OF HEALTH CARE**
RESOURCES **Daniels**

1. N. Daniels, *Just Health Care* (Cambridge, 1985), chapters 2 and 3.
2. A. Buchanan, "The Right to A Decent Minimum of Health Care," *Philosophy & Public Affairs* (1984), pp. 55-78.
3. R. Dworkin, *Sovereign Virtue* (Harvard, 2000), ch. 8.

February 19 **JUSTICE AND THE ALLOCATION OF HEALTH CARE**
RESOURCES **Sreenivasan**

1. Dan Brock, "Ethical Issues in the Use of Cost-Effectiveness Analysis for the Prioritization of Health Care Resources."
2. Frances Kamm, "Health and Equity."
3. Norman Daniels and James Sabin, "Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers, *Philosophy & Public Affairs* (1997) 26, 4: 303-350.

February 26 **ETHICS AND MANAGED CARE** **Pearson**

1. Sabin JE, Daniels N. "Strengthening the Consumer Voice in Managed Care: I. Can the Private Sector Meet the Public Sector Standard? *Psychiatric Services* 2001; 52(1):461-462/64.
2. Pearson SD. "Caring and Cost: The Challenge for Physician Advocacy." *Annals of Internal Medicine* 2000; 133(2):148-153.
3. Robinson JC. "The End of Managed Care." *JAMA* 2001; 285(20): 2622-2628.
4. Hasan MM. Sounding Board "Let's End the Nonprofit Charade." *New England Journal of Medicine* 1996; 334(16): 1055-1057.

March 5 **PROCREATION OR MANUFACTURE?** **Kass**

1. Kass, LR, Wilson, JQ. *The Ethics of Human Cloning*. 1998. AEI Press.
2. Kass, LR. "Preventing a Brave New World." *The New Republic* May 21, 2001.

March 12 **ALTERNATIVE REPRODUCTIVE TECHNOLOGIES**
Steinbock

1. Steinbock, B. "Regulating Assisted Reproductive Technologies: An Ethical Framework," *Women's Health Issues* 6:3 (May/June 1996), pp. 1-8
2. Steinbock, B. "A Philosopher Looks at Assisted Reproduction," *Journal of Assisted Reproduction and Genetics* 12:8 (1995), pp. 543-551
3. Steinbock, B. "What Does 'Respect for Embryos' mean in the Context of Stem Cell Research?" *Women's Health Issues*, Vol. 10, no. 3 (May/June 2000), pp. 127-130

4. Steinbock, B. "The Moral Status of Extracorporeal Embryos: Preborn Children, Property or Something Else?" in Anthony Dyson and John Harris, eds., *Ethics and Biotechnology* (London and New York: Rutledge, 1994), pp. 79-92.
5. Steinbock, B. "Payment to Egg Donors", *Mount Sinai Journal of Medicine* (forthcoming 2002)
6. Steinbock, B. "Sex Selection: Not Obviously Wrong, "Hastings Center Report (forthcoming, March-April 2002).

*Suggested reading: Steinbock, B. "Preimplantation Genetic Diagnosis and Embryo Selection," in , A Companion to Genetics: Philosophy and the Genetic Revolution, Justine Burley and John Harris, eds., Blackwell Publishers, 2001

March 19

FEMINISM

Carse

1. Wolf SM. "Gender and Feminism in Bioethics" in *In Feminism and Bioethics: Beyond Reproduction*. Susan M Wolf, Ed. New York: Oxford Press 1996; pp4-43.
2. Baier AC. "The Need for More Than Justice" in *Moral Prejudices*. Cambridge: Harvard University Press 1994; pp18-32.
3. Carse AL. "Facing Up to Moral Perils: The Virtues of Care in Bioethics." *Journal of Medicine and Philosophy* 1991; 15: 5-28.
4. Little MO. "Why a Feminist approach to Bioethics?" *Kennedy Institute of Ethics Journal* 1996; 6(1): 1-18.
5. DeBruin DA. "Justice and the Inclusion of Women in Clinical Studies: An Argument For Further Reform." *Kennedy Institute of Ethics Journal* 1994; 4(2): 117-146.

MARCH 26TH

VACATION

MARCH 26TH

April 2nd

Moral Theory

Richardson

1. Cruzan v. Director, Missouri Dept Health, 497 US 261 (1990)(on the right to refuse life-sustaining treatment)
2. SM Wolf et al., Sources of Concern About the Patient Self-Determination Act, *New Engl J Med* 325:1666-1671(1991)(on problems with federal legislation on advance directives)
3. Minnesota Statutes Annotated chs. 145B-145C (West 2002) (on problems with state statutes on advance directives)
4. Arato v. Avedon, 858 P2d 598 (Cal. 1993)(on informed decision making at the end of life)
5. McKay v. Bergstedt, 801 P2d 617 (Nev. 1990)(on the line between termination of treatment and assisted suicide)

April 9

LEGAL CASES IN TERMINATING CARE

Forster

1. Meier, D, Emmons, C-A, Wallenstein, S, Quill, T, Morrison, R.S., Cassel, C; A National Survey of Physician-Assisted Suicide and Euthanasia in the United States; *The New England Journal of Medicine*; April 1998, 338:1193-1201.
2. Meier, D, Myers, H, Muskin, PR; When a Patient Requests Help Committing Suicide; *Care at the end of Life: Restoring Balance*, Spring 1999 61-68
3. Muskin, PR; The Request to Die-Role for a Psychodynamic Perspective on Physician-Assisted Suicide; *JAMA*; January 28, 1998 279 (4) 323-328
4. Breitbart, W, Rosenfeld, B, Pessin, H, Kaim, M, Funesti-Esch, J, Galiotta, M, Nelson, C, Brecia, R; Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients With Cancer; *JAMA*, December 13, 2000 284, (22) 2907-2911
5. Meier, DE, Back, AL, Morrison, RS; The Inner Life of Physicians and Care of the Seriously Ill; *JAMA*, December 19, 2001 286 (23) 3007-3014
6. Kade, WJ; Death with Dignity: A Case Study; *Annals of Internal Medicine* 132(6) 504-506
7. Emanuel, LL; Facing Requests for Physician-Assisted Suicide; Toward a Practical and Principled Clinical Skill Set; *JAMA* August 19, 1998 280 (7) 643-647

April 16

Euthanasia and PAS

1. Scheffler, Samuel; *Consequentialism and its Critics*, Oxford University Press
2. William, Bernard; *Consequentialism and Integrity; The structure of consequentialism*, (Cambridge University Press) 1973.
3. Scanlon, T.M.; *Rights, Goals, and Fairness, from Public and Private Morality*, ed. Stuart Hampshire (Cambridge University Press, 1978), pp. 74-92.
4. Nozick, Robert; *Side Constraints; The Minimal state and the Ultraminimal state*, Basic Books, Inc. 1974, pp. 135-141
5. Railton, Peter; *Alienation, Consequentialism, and the Demands of Morality*; Princeton University Press.

April 23

Advance Directives

Lavery

1. Emanuel, EJ. Euthanasia and Physician-Assisted Suicide; A Review of the Empirical Data from the United States, *Archives of Internal Medicine*, vol. 162, (Jan 28, 2002) pp. 142-152
2. The Oregon Death with Dignity Act
3. Annas, GJ. Death by Prescription; The Organ Initiative, *NEJM* (Nov. 3, 1994) pp. 1240-1243.
4. Hurst, S. Maron, A. Letter from Switzerland; Assisted Suicide and Euthanasia: A Role for Everyone? (Draft --JAMA 2002).

April 30th

CONFLICT OF INTEREST

Stark

1. Dennis F. Thompson, "Sounding Board: Understanding Financial Conflicts of Interest." *New England Journal of Medicine* 329: 573-576, (August, 19 1993).
2. Ezekiel J. Emanuel, M.D. and Daniel Steiner, "Sounding Board: Institutional Conflict of Interest." *New England Journal of Medicine* 332, No.4: 262-267, (January 26, 1995).

3. Kenneth J. Rothman, "Conflict of Interest: The New McCarthyism in Science." *JAMA* 269, No.21: 2782-2784, (June 2, 1993).
4. Dennis F. Thompson, *Ethics in Congress*, (Washington: Brookings, 1995), pp. 124-130.
5. Bernard Shaw, *The Doctor's Dilemma: A Tragedy, definitive text*. (Harmondsworth: Penguin, 1975), pp. 7-8.
6. Stephen R. Latham, "Conflict of Interest in Medical Practice," in *Conflict of Interest in the Professions*. Eds. Michael Davis and Andrew Stark (Oxford, 2001), pp. 285-301.
7. *The Wall Street Journal*, November 11, 1994. Thomas M. Burton, "Fee for Service: Caremark Faces Heat for Paying Doctors Who sent it to Patients."
8. *The New York Times*, October 4, 1994. Lawrence K. Altman, M.D., "The Doctor's World."
9. *The New York Times*, April 4, 1998. Sheryl Gay Stolberg, "Gifts to Science Researchers Have Strings, Study Finds."
10. *The New York Times*, February 20, 2000. Sheryl Gay Stolberg, "Biomedicine is Receiving New Scrutiny as Scientists Become Entrepreneurs."
11. *The New York Times*, March 4, 2002. Walt Bogdanich, "2 Powerful Groups Hold Sway over Buying at Many Hospitals."

May 7

Bioethicists Inside the Beltway

Dresser

1. 1.Wilfond BS, Molan K. National Policy Development for the Clinical Application of Genetic Diagnostic Technologies: Lessons from Cystic Fibrosis. *JAMA* 1993, 270:2948-2954.
2. 2.Wilfond BS, et. al. Cancer Genetic Susceptibility Testing: Ethical and Policy Implications for Further Research and Clinical Practice *J Law Med and Ethics* 1997 25:243-251.
3. 3.Geller G et. al. Genetic Testing for Susceptibility to Adult-Onset Cancer. *JAMA* 1997, 277:1467-1474.
4. 4.Welch GH, Burke W. Uncertainties in Genetic Testing for Chronic Disease. *JAMA* 1998 280:1525-1527.
5. 5.Holtzman NA, et. al. Predictive Genetic Testing: >From Basic Research to Clinical Practice. *Science*, 1997 278:602-604.

May 14

Ethics and Genetic Testing

Botkin

1. Botkin, JR "Protecting the privacy of family members in survey and pedigree research", *JAMA* (2001); 285 (5) pp. 207-211.
2. NIH committee report by Sara Carr and Jim Hanson on the "third party" consent issue. "Protection of Third Party Information in Research: Recommendations of the National Institutes of Health to the Office for Human Research Protections", December 7, 2001

May 21

ORGAN TRANSPLANTATION

Veatch

May 28

CROSS-CULTURAL BIOETHICS

Gbadegesin

1. Christakis NA. "Ethics are Local: Engaging Cross-Cultural Variation in the Ethics for Clinical Research." *Social Science Medicine* 1992; 35(9): 1079-1091.
2. Baker R. "A Theory of International Bioethics: Multiculturalism, Postmodernism, And the Bankruptcy of Fundamentalism." *Kennedy Institute of Ethics Journal* 1998; 8(3): 201-231.
3. Baker R. "A Theory of International Bioethics: The Negotiable and the Non-Negotiable." *Kennedy Institute of Ethics Journal* 1998; 8(3): 233-274.
4. Beauchamp TL. "The Mettle of Moral Fundamentalism: A Reply to Robert Baker." *Kennedy Institute of Ethics Journal* 1999; 8(4): 389-401.
5. Macklin R. "A Defense of Fundamental Principles and Human Rights: A Reply to Robert Baker." *Kennedy Institute of Ethics Journal* 1999; 8(4): 403-422.
6. Baker R. "Negotiating International Bioethics: A Response to Tom Beauchamp and Ruth Macklin." *Kennedy Institute of Ethics Journal* 1999; 8(4): 423-453.

June 4

Ethics in Public Health

Brock

1. Weisbard AJ. The role of philosophers in the public policy process: a view from the President's Commission. *Ethics* 1987; 97:776-785.
2. Brock D. Truth or Consequences: The Role of Philosophers in Policy-Making. *Ethics* 1987; 97:786-791.
3. Kamm FM. The Philosopher as an Insider and an Outsider. *The Journal of Medicine and Philosophy* 1990; 15:345-374.
4. Benjamin M. Philosophical Integrity and Policy Development in Bioethics. *The Journal of Medicine and Philosophy* 1990; 15: 375-389.
5. *Kymlicka W. Moral Philosophy and Public Policy. *Bioethics* 1993; 7:1-26.
6. Momeyer, Richard W. 1990. "Philosophers and the Public Policy Process: Inside, Outside, or Nowhere at All?" *The Journal of Medicine and Philosophy* 15(August): 391-410.
7. Wikler, D. "Bioethics as a Global Enterprise," in Z. Bankowski and J.H. Bryant, eds., *Poverty, Vulnerability, and the Value of Human Life: A Global Agenda for Bioethics*, pp. 209-214 (Geneva: CIOMS, 1995)

June 11th

The Theory of Ethics Consultation

Danis

1. Casarett DJ, Daskal F, Lantos J "Experts in Ethics?: The Authority of the Clinical Ethicist", *Hastings Center Report* 28 vol.6 (1998):6-11.
2. Fletcher JC, Siegler M, "What are the Goals of Ethics Consultation: A Consensus Statement, *The journal of Clinical Ethics*, Summer 1996, vol. 7, 2:pp122-126.
3. Moreno JD, Ethics by Committee: "The Moral Authority of Consensus", *The Journal of Medicine and Philosophy* 13 (1988): pp.411-432.
4. Urban Walker M, Keeping Moral Space Open: New Images of Ethics Consulting, *Hastings Center Report*, March-April 1993, pp.33-40
5. Ross JW, John MA, Glaser JW, S.T.D., et al, Case Consultation and Review: Matching Skills and Expectations. Chapter 7 pg; 91-107

6. Wolf SM, "Toward a Theory of Process", *Law, Medicine and Health Care* vol. 20:4 (1992) 278-290.
7. American Society for Bioethics and Humanities, Core Competencies for Health Care Ethics Consultation; Report of the ASBH Task Force initiated spring of 1997 at the Society for Health and Human Values Conference Loyola University of Chicago., pp. 1-48.